LOCAL COURT
New South Wales
Wollongong

Jurisdiction:	Coronial
Matter	Inquest into the death of TY LACEY
Hearing dates:	12, 13, 14, 15 November 2012
Date of Findings:	11 December 2012
Findings of:	Ian Guy Deputy State Coroner, Wollongong
Representation:	Dr P Dwyer, Barrister, Counsel Assisting, instructed by Mr L Chee of Department of Attorney General and Justice. Mr G Smith, Barrister for the family Mr M Windsor SC instructed by NSW Crown Solicitor's Office for the Illawarra and Shoalhaven Local Health District, South Eastern Sydney Local Health District, Professor Welsh, Dr Challis, Dr Wanat Mr I Butcher, Barrister for Dr Davis Ms Doust, Solicitor for Registered Nurses Kerle and Conte

Reasons for Findings

1. In October 2009 Mrs Myliss Lacey was excited to learn she was pregnant. Scans revealed she was expecting twin boys, who the parents named Cruz and Ty.

2. The twins were sharing the one placenta and Mr and Mrs Lacey became concerned when there was an apparent growth discrepancy. The couple attended Wollongong Hospital on a number of occasions and were worried about the progress of the twins and symptoms Mrs Lacey was experiencing during the early stages of the pregnancy. There was also a sense of frustration felt by them about their treatment and lack of continuity of care by Medical staff.

3. It was the ultra sound performed on 27 January 2010 that first supported the parent's suspicions Twin To Twin Transfer Syndrome (TTTS) had developed. This syndrome produces an abnormal exchange of blood supply between the twins that can often lead to fatal outcomes to one or both.

4. Mr and Mrs Lacey were referred for specialist care at the Royal Hospital for Women, Sydney. Further tests confirmed the syndrome and that it had advanced to the stage where the twin Cruz died in utero. There were extensive discussions with the family as to the risks of death or severe disability for the twin particularly in the event of an early labour. It appears discussion involved the question of whether there should be resuscitation of Ty if he was born at less than 26 weeks gestation, although there is some dispute as to whether the parents had agreed to a birthing plan.

5. On 15 February 2010 and at 24.2 weeks gestation, Mrs Lacey went into labour. She was in what is described as the "grey zone" for the viability of a baby surviving at such an early stage of life.

6. Mr and Mrs Lacey attended Wollongong Hospital. Staff were told they wanted everything done to save Ty including a caesarean section and transfer to Sydney. Her labour was so advanced that transfer was not possible. Dr Wanat, senior Obstetric and Gynaecology Registrar telephoned the Royal Hospital for Women for advice given the extreme prematurity of Ty and the TTTS syndrome. He was told of the poor prognosis and that he should speak with the parents to find out what they wanted concerning resuscitation.

7. Dr Wanat failed to consult with the parents and explain the options available. He gave the parents no option other than Ty was not to be resuscitated. Ty was born alive and was held by Mrs Lacey for approximately half an hour before he died. The parents were not prepared for the shock of delivering Cruz stillborn and the anguish of Ty dying in such circumstances despite their request for assistance.

8. A Hospital review of the death by way a Morbidity and Mortality meeting and a subsequent Hospital investigation apparently concluded the option of non-resuscitation was appropriate.

9. Dr Wanat issued a Death Certificate recording the cause of death as extreme prematurity. On the basis of the evidence at inquest, it is probable the medical cause of death is as recorded on the certificate.

10. The matter became a Coroner's case when the parents contacted Senior Constable Coventon-McKenna to complain about the treatment provided and in particular the decision not to resuscitate. The investigation started from that phone call.

11. From this brief outline the following issues emerge—

- What are TTTS, the grey zone and what were Ty's chances?
- The care and treatment provided at Wollongong Hospital.
- The care and treatment provided at Royal Hospital for Women.
- The events at Wollongong Hospital on 15 February and the decision not to resuscitate.
- The response by Wollongong Hospital.
- The question of Recommendations

The nature of an Inquest

12. Before turning to the issues, it is important to briefly outline the nature of an inquest. The role of the Coroner is limited by statute in particular under section 81 of the Corner's Act 2009 to return a finding where there exists sufficient evidence, as to the identity of the deceased, the date, place, manner and cause of death. An inquest is not adversarial in nature. It is neither a criminal nor civil proceeding.

13. Section 82 of the Act allows for recommendations to be made by the Coroner as considered necessary or desirable in relation to any matter connected with the death the subject of inquest.

14. Apart from the statutory functions and power to make recommendations, an inquest may serve the important function of enabling family members to better understand the circumstances surrounding the death of a loved one.

15. The main focus of this inquest has been the manner (that is the surrounding circumstances) of Ty's death and any recommendations that may flow. It should be noted is not the function of the Coroner to make formal findings of negligent behaviour on the part of any particular health professional. Nor is the Coroner's role to sit as a type of medical misconduct Tribunal. Where specific or systemic failings of an individual or organisation are identified, any commentary or findings are done so in the context of determining the manner of death.

Issue 1 –TTTS, the Grey Zone and Ty's chances

16. Cruz and Ty were mono-chorionic twins that are identical twins who shared a single placenta. The placenta is the organ connecting the developing foetus to the internal wall of the mother to allow nutrient uptake and waste elimination. Sharing a placenta occurs in about two thirds of identical twins.

17. TTTS is a rare condition affecting about five to ten % of mono -chorionic twins. It essentially involves a disproportionate blood supply between the twins through connecting blood vessels within the placenta. There is then blood being “donated” by one twin to the other. The donor twin has decreased blood volume affecting the donor twins development and growth and a lower level of amniotic fluid. Twin two becomes the “recipient” of an abnormally high supply of blood that can cause a strain on the twin’s heart. The twin produces a higher than normal urinary output increasing the amniotic fluid. The variation in the amniotic fluid as between the twins is detected by ultrasound and is the method for detection of the syndrome.

18. Dr Challis, Senior staff specialist Maternal Foetal Medicine, Royal Hospital for Women Sydney, observed it is a highly unpredictable condition and may worsen rapidly. It can also resolve spontaneously in milder conditions. Prior to advances in treatment that includes laser therapy, there was nearly 100% mortality.

19. Dr Gardener, Director of Maternal Foetal Medicine at Mater Mothers Hospital Queensland explained there are a number of stages of TTTS. Stage one involves a disproportionate level of amniotic fluid between the twins. The subsequent stages involve increased health problems to the twins. Stage five involves the death of one or both in utero.

20. Twin Cruz died prior to birth. Ty was born at 24.2 weeks gestation in what the experts call the grey zone of viability. A Consensus Statement reproduced in the 2006 Australian Medical Journal notes the improvements in Perinatal care of extremely premature babies and the international debate on the management of neonates at the threshold of viability[1]. The Consensus Statement concluded neonates at less than 23 weeks had such physical and neurological problems they were outside the realm of viability. Neonates with a gestation from 26 weeks were considered viable; the extent of viability increasing as each week passes. Those born between 23 and 25 weeks are viewed in the grey zone of viability.

21. For many reasons the experts differed on their assessment whether Ty would survive and without major and lifelong disabilities. Studies and percentage outcomes will be interpreted in a variety of ways. Issues will arise as to the size of a sample to make meaningful conclusions and comparisons.

22. There were numerous risk factors weighing against for Ty born at 24.2 weeks gestation. They included his extreme prematurity, the TTTS syndrome itself, the death of the other twin from TTTS, the fact Ty was male, the absence of steroids sufficiently ahead of the birth and delivery in a regional Hospital.

23. Professor Evans, Clinical Professor in Neonatal Medicine at Royal Prince Alfred Hospital and University of NSW, saw the chances of Ty’s survival with active resuscitation at less than 10%. Dr Gardener considered there was a 60-70% risk of death if resuscitated and transferred to a tertiary facility and a 60-

[1] Brief p 491

70% risk of severe disability. Combining these figures, he said there was about a 15% chance Ty would survive and not suffer a severe disability. Dr Challis and Professor Welsh viewed the figures as “optimistic”.

24. It is unnecessary to determine a precise percentage figure. There was universal common ground that Ty’s death or his sustaining a major degree of disability was not inevitable; it wasn’t a certainty. This leads to the vital issue – who decides whether there should be active resuscitation and intensive care?

25. The Consensus Statement noted it is acceptable medical practice not to initiate intensive care if the parents wish, after appropriate counselling[2]. The theme of the Consensus Statement is offering the parents options, not removal of the parents’ wishes and substitution by the Doctor.

26. The 2010 Resuscitation Guidelines makes some important observations. Resuscitation does not mandate continued support. If there is doubt whether to initiate or withhold resuscitation it is best to start and later withdraw treatment when there is clarification of the situation. In conditions associated with uncertain prognosis where there is borderline survival and a relatively high rate of morbidity and where the burden on the child is high, the parents’ view on resuscitation should be supported[3].

27. Independent of Guidelines, the experts are clear. It is for the parents to decide. It is the parents who will be called upon to assume the burden of caring for a potentially severely disabled child. Some examples suffice—

- Professor Welsh -- For parents in the grey zone it is for the parents to decide; a matter of informed choice
- Dr Challis -- The ultimate decision on resuscitation rests with the parents
- Dr Gardener -- Advice would be given concerning the poor prognosis but ultimately leaving it to the parents and being completely supportive of them whatever decision they make

28. The summary of the experts’ views to involve the parents and support them in their decision reflects in my view absolute commonsense in medical care.

Issue 2 --The care provided at Wollongong Hospital prior to 15 February 2010

29. Mrs Lacey’s general practitioner referred her to Wollongong Hospital antenatal unit. A booking was taken on 9 November 2009 and an ultra sound scan was planned. On 13th of November 2009 the scan reported twins sharing the one placenta with twin one less than expected for his gestational age. A follow-up appointment was arranged.

30. On 23 November 2009 a further scan noted the foetal measurement for twin one was at the lower limit of normal for gestational age. A follow-up appointment was arranged. Mrs Lacey had an appointment at the antenatal

[2] Brief p491
[3] Brief p 559

clinic on 2 December 2009 with a Midwife. On 16 December they saw for the first and only time Dr Davis, Clinical Director of Maternal and Paediatric Services for Illawarra Shoalhaven Local Health District. At the inquest, Mr and Mrs Lacey expressed their concerns at the relatively short time they had spent with Dr Davis and what was said to be a lack of information given in response to concerns the parents held that the scans may be suggestive of a yet undiagnosed TTT syndrome.

31. It was at this meeting with Dr Davis that Mr and Mrs Lacey raised the question whether they should go to Westmead Hospital for expert treatment. They say they were advised it was up to them to decide. They had in fact planned to temporarily move to a family members house in the Westmead area in the hope of maximising the chances of a good outcome for the twins.

32. A further ultrasound was conducted on 30 December 2009. At this stage Mrs Lacey was about 12.5 weeks pregnant. Both twins were considered as within normal limits but there was a continuation of the relative growth difference. On 4 January 2010,Mrs Lacey attended the antenatal clinic requesting a referral to Westmead. A doctor assured her they would be contacted once that doctor had discussed the request with Dr Davis. No contact was in fact made.

33. On 11 January 2010,a further ultrasound was conducted, again finding the twins were within normal limits apart from the growth discrepancy. Mr and Mrs Lacey said although they remained concerned, their spirits were improving with each scan.

34. On 13 January 2010,they returned to the Hospital seeing a different Doctor. They repeated their history and ultimately a referral was given for Westmead Hospital.

35. On 17 January 2010, Mrs Lacey went back to Wollongong Hospital complaining of tightening of the stomach and lower back pain. An ultrasound was carried out. Mrs Lacey was reassured by staff and returned home.

36. Mrs Lacey returned on 22 January 2010 with similar symptoms. She was again told her symptoms related to her small frame and told to return home.

37. On 27 January 2010 Mrs Lacey again returned to the Hospital and became upset her underlying concerns that the symptoms were from TTTS were being ignored. Staff did not offer her an ultrasound, but by coincidence she had an ultrasound appointment that day. It showed a disparity in the amniotic fluid as between the twins, being a strong indicator of the existence of the syndrome. Mrs Lacey then returned to Wollongong Hospital. She was unable to see Dr Davis but ultimately seen by a Registrar who organised an appointment at the Royal Women's Hospital the following morning.

38. Dr Gardener considered Mrs Lacey’s care at Wollongong Hospital in the treatment of the TTTS was appropriate. There were regular ultrasounds conducted and it is to be observed the syndrome cannot be detected until the disparity in the amniotic volume is seen on ultrasound. The referral to the

Royal Hospital for Women was timely upon the Hospital becoming aware of the syndrome.

39. However what did emerge in the clearest of terms at the inquest was the high degree of frustration and distress the parents felt from the absence of continuity of Doctor care. It would appear they did not see the same Doctor more than once. At a time of immense stress and worry there was a need to recite the medical history to each new Doctor.

40. Mr and Mrs Lacey felt their concerns about possible TTTS were not being treated seriously. It transpired from the evidence of Dr Gardener that the symptoms relayed to staff are consistent, although not exclusively, with the syndrome.

41. At the inquest the Hospital highlighted the difficulties of a public patient in a public Hospital having continuity of care. There was nevertheless an acknowledgement the Hospital is working to improve rostering and continuity of care. It is a matter that will be included in the Recommendations.

Issue 3—The care and treatment by the Royal Hospital for Women

42. Professor Welsh saw Mrs Lacey on 28 January 2010. An ultra sound was performed that day and stage one of TTTS was identified. A follow up ultra sound was conducted on 29 January. The syndrome had progressed significantly and the diagnosis was stage three. Professor Welsh considered the only option to endeavour to save both twins was laser surgery.

43. Dr Gardener considers both the timing of the planned operation and the proposed procedure to have been both timely and appropriate. Unfortunately, the planned procedure could not proceed as an ultra sound showed twin Cruz was deceased.

44. A subsequent ultrasound was conducted on 30 January that showed Ty was active but with signs of diminished blood volume. A further ultrasound was conducted showing Ty to be active and less anaemic. An MRI scan was also conducted that was negative for any gross brain abnormalities in the surviving twin. A further ultra sound conducted on 4 February showed Ty to be “biophysically well”. It was explained at the inquest there might nevertheless be significant underlying neurological deficits.

45. On 6 February, Mrs Lacey was readmitted to the Royal Hospital for Women for 3 days for a suspected rupture of the membranes when she was 23 weeks gestation.

46. It is clear Professor Welsh gave detailed advice of the danger to the remaining twin and the possible adverse outcomes. The parents were complimentary of the efforts of Professor Welsh and the time he had spent with them to discuss the many difficult issues surrounding TTTS and the possible prognosis for Ty. They felt at the time reassured he had the expertise and understood their concerns.

47. Dr Gardener views the care as appropriate. There can be no criticism of the Hospital or its staff. The only point of disagreement between Professor Welsh and the parents is the existence of a treatment or birthing plan noted in Hospital records following a meeting on 7 February 2010.

48. Professor Welsh says the notes he prepared after his meeting with the parents reflected what he believed to be an agreed position, subject to change at any time, in the event that Mrs Lacey went into early labour. The note relevantly referred that in the event of labour less than 26 weeks, there be no resuscitation, a vaginal birth and no steroids (which can have a positive effect on lung capacity).

49. From Mr and Mrs Lacey's perspective, although some of these matters were discussed there was in fact no agreement by them this was to occur. When told how a termination would occur she said she told Professor Welsh she couldn't possibly kill her child.

50. There are difficulties in making conclusive findings as to what was agreed at the meeting and for reasons that will become clear it is of markedly less significance than what occurred at Wollongong Hospital on 15 February. On one view, the notes were written immediately after the discussion following a lengthy discussion and apparently the plan was discussed at meetings with colleagues. From the Lacey's viewpoint, they did not see the notes or adopt them and there were comments by Mr Lacey during the inquest that might suggest a lack of understanding of some of the terms used in the "plan". There were also comments from Professor Welsh that it did not represent a management plan, it was not intended to bind another Doctor and they represented issues that were discussed and have to be considered in the future; "they were important issues to think about".

51. I do not believe it necessary to delve into the dispute about the recollection of events. It is irresistibly clear it was not a binding document nor was it ever intended to be. Nor can it be said on 15 February at Wollongong Hospital Dr Wanat merely followed a plan created elsewhere. For as was made abundantly clear by Professor Welsh the advice or plan was dynamic and open to discussion and change at any time.

52. What this aspect of the evidence in the inquest did raise was the difficult issue of management or birthing plans. Views were mixed as to the appropriateness of having a more formal management plan. I will return to this issue when considering the Recommendations.

Issue 4 –The events at Wollongong Hospital on 15 February 2010

53. In the early hours of the 15 February 2010, Mrs Lacey began experiencing labour pains. She and her husband drove to Wollongong Hospital. On the way they discussed and agreed what they wanted; namely to give Ty every chance to survive.

54. Mrs Lacey went to a consulting room while Mr Lacey parked the car. Nurse Conte confirmed that Mrs Lacey told her she wanted everything done to save Ty. She asked for steroids to help lung capacity, a c-section (she had read it would be less traumatic on the baby) and transfer to Sydney. Mr Lacey arrived a short time later. He says he told Dr Wanat they wanted a c-section, transfer to Sydney, resuscitation and Dr Wanat agreed to this request. There is support for this account. Steroids were given and can only be with the authorisation of the Doctor. The topic of a caesarean section was raised as it was discussed between Dr Challis at the Royal Hospital for Women and Dr Wanat. The fact the neonatal intensive care team were on standby to transport Ty only reinforces the conclusion the parents had conveyed their wishes in the clearest of terms.

55. Dr Wanat was prepared to acknowledge when he left the consulting room to make a call for advice, he "most probably" understood the parents wanted everything done. I am satisfied it was more than most probably. I accept Mr Lacey made clear to him their wishes.

56. Dr Wanat was aware of the TTT syndrome and the early gestation of the surviving twin. He spoke with Dr Davis at Wollongong Hospital who in turn recommended he contact the Royal Hospital for Women for advice given they were involved in her care. Professor Welsh was not available and Dr Wanat spoke with Dr Challis.

57. Dr Challis says he was aware of Mrs Lacey's background, having initially been requested to assist in the planned laser surgery and also from meetings where patient cases were discussed. He understood at the time the Lacey's birthing plan was not for resuscitation less than 26 weeks gestation.

58. Dr Challis says the telephone call was brief. He recommended there be no caesarean section given the surgical difficulties and the potential risk to the mother. He advised the baby had a poor prognosis in view of the extremely early gestation, small estimated size, location of the birth outside the tertiary centre and that he should involve the on-call consultant paediatrician in the decision and the couple should be made aware of the poor outlook. He said if the couple asked for their advice it would be reasonable to offer no resuscitation[4].

59. Dr Challis made clear at the inquest although he outlined what he understood to be the plan he told Dr Wanat to have discussions with the family and work out what they wanted. This recommended course accords with his inevitable practice at his Hospital and simply accords with common sense that you would recommend discussing a matter of such importance with the parents. Dr Wanat says although he cannot now remember it is most probable Dr Challis did suggest he speak with the family.

60. According to Dr Wanat he then went to speak again with Dr Davis who was involved in an unrelated operation and confirmed the management plan. Dr

[4] Brief p 66

Davis has no recollection of this conversation but in any event, there is nothing to suggest confirmation of the plan was to be without input and agreement from the parents.

61. Dr Wanat returned to the birthing unit. According to Mr Lacey, Dr Wanat said –

> “I am so sorry I just got off the phone from Randwick Women's Hospital and spoke to Dr Challis. I'm sorry we are not going to do a c-section and I have been told not to help.
>
> Mr Lacey: What do you mean?
>
> Dr Wanat: ”He has just too much stacked up against him he is just not going to make it I'm sorry.”

62. Mr Lacey relayed this to his wife saying –“Its all over babe”. The parents cried with Mrs Lacey describing the news as crushing[5]. It was shortly after that Cruz was stillborn. Neither parent was warned what to expect with a stillborn baby and became highly distressed at his appearance.

63. Mr and Mrs Lacey’s account of events on 15 February 2010 was plausible, logical and internally consistent. Their evidence on this aspect was not in any way shaken during the inquest. Nurse Conte’s account supports the parents’ assertion there was no discussion about options. When Dr Wanat returned after making the telephone call he said the baby was not for resuscitation; that he discussed with the parents he had spoken to the doctors that the baby was small and should not be resuscitated.

64. Even Dr Wanat’s version supports the parents account there was no meaningful discussion. He said he relayed what he had been told by Dr Challis and the plan the parents had discussed with Professor Welsh, telling them he is sorry but given the baby was arriving at 24 weeks there is nothing else to be done.

65. There is support for the account they were told by Dr Wanat the baby would not survive labour. Nurse Conte confirms when a relative asked at one stage why they were not listening for a heartbeat, Mrs Lacey replied the baby was too small to survive.

66. Dr Wanat advanced the birth of Ty by artificially breaking Mrs Lacey’s waters. Ty was born alive shortly after, crying and moving. He was wrapped in a towel and handed to his parents. A warm blanket for Ty was not provided. It is clear Mrs Lacey asked Dr Wanat to help Ty and that he replied, “I'm sorry”.

67. Mrs Lacey says the artificial breaking of her waters was done without her consent. She had been told previously that every minute and hour would give him a better chance of survival. The Hospital says she consented to medical treatment upon her arrival. I do no think it necessary to delve into issues of

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[5] Brief p 43

ongoing consent. What this aspect of the evidence does highlight however is the action of breaking her waters to advance labour and the birth of Ty does not sit comfortably with Dr Wanat's evidence that he was seeking a second opinion as to resuscitation. It is inconsistent with seeking to delay the process to obtain an opinion and more consistent with putting into effect what he had determined after the phone call. There was then no point delaying events.

68. Ty survived for approximately 24 minutes. The parents' statements refer to a longer period of time. I am satisfied the Hospital records are accurate and the difference can be explained by the stress the parents were experiencing. Mr Lacey sums up the impact upon them when he said –

> "What was to come was the most horrific and heartbreaking experience I have ever had to endure, to watch my son try to breathe and hold onto life while he slowly turned blue in the face. It was devastating"[6].

69. Whilst it is acknowledged the events did not lend itself to calm discussion, staff told neither parent what to expect when no active resuscitation is given. It was not only the parents who were unprepared for the devastating events after Ty was born. A very experienced midwife had not previously witnessed an event where no active resuscitation was given to a baby. She very appropriately arranged counselling to deal with what she experienced. It is clear staff were not trained and equipped to deal with such situations. The result is the quality of care to the parents must necessarily be compromised.

70. Reference should now be made to some of the oral and written statements by Dr Wanat concerning the decision not to resuscitate.

71. At the inquest he said Dr Challis advised him the plan of management should be to offer her baby childbirth, no caesarean section and no active resuscitation. It is very difficult to understand how an "offer" became no option at all.

72. In a written statement, Dr Wanat said —

> "The couple were informed of the plan and accepted it"[7].

73. This is simply incorrect. He presented them with no options other than making clear the baby was not for resuscitation and would not make the labour. The suggestion by Dr Wanat at the inquest that there was "like an open discussion" with Mrs Lacey is something I do not accept.

74. Dr Wanat further said –

> "I spoke with Mrs Lacey and her husband about what I had been told by Dr Challis and the plan they had talked about with Professor Welsh. I

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[6] Brief p 43
[7] Brief p104

told them I was sorry but given the baby was arriving at 24 weeks there was nothing else to be done[8].

75. This statement is also disturbingly incorrect. Dr Challis did not tell him not to resuscitate. He said to speak to the parents and find out what they wanted. There were in fact options available as explained by Dr Gardener[9]. He noted the possible options that should have been considered and discussed with the parents on 15 February 2010 were --

1. Vaginal delivery, no initiation of resuscitation
2. Vaginal delivery, paediatric assessment of newborn and initiation of resuscitation if appropriate, neonatal transfer to tertiary centre as indicated
3. Steroids and tocolysis to delay delivery, antibiotics, planned vaginal delivery, paediatric assessment of the newborn and initiation of resuscitation if appropriate, neonatal transfer to tertiary centre as indicated
4. Steroids and tocolysis to delay the delivery, antibiotics, planned caesarean section, paediatric assessment of the newborn and initiation of resuscitation if appropriate, neonatal transfer to tertiary centre as indicated.

76. In a written statement Dr Wanat said –

> ‘‘It appeared to me that Mrs Lacey accepted the baby would not be resuscitated.”[10].

77. The “acceptance” by Mrs Lacey was imposed upon her by the absence of discussion, telling her there will be no resuscitation and the baby was too small to survive labour.

78. Dr Wanat said –

> “Mr and Mrs Lacey never asked me to resuscitate the baby either before or after his birth”.[11]

79. The word “resuscitate” may not have been specifically used but it is artificial to overlook the compelling evidence he was told they wanted everything done to save the baby. It is simply disingenuous to suggest they didn't ask for resuscitation after the baby was born. It is clear Mrs Lacey did ask him “why can’t you help him”. Dr Wanat acknowledged she probably did ask. It is clear any failure to ask for “resuscitation” was the product of providing parents with no options other than there being no resuscitation.

80. Dr Wanat said at the inquest after his call with Dr Challis he was thinking there is really no chance for the survival of the second twin. This is at odds

[8] Brief p 57
[9] Brief p 129
[10] Brief p 59
[11] Brief p 59

with Dr Challis's evidence that he told Dr Wanat of the poor prognosis, not that there was no chance of survival. This understanding from the call does not sit comfortably with his later evidence that he did not think the baby would survive without severe disability. In either case, it was clearly for the parents to decide.

81. Reference should be made to the Hospital records created by Nurse Heaven following a home visit on 18 February that reads in part---"concerned that she? made the correct/not correct decision not to resuscitate the baby. Felt she always thought she would do everything to save her baby but does not know why she declined when faced with the decision".[12]

82. The notes do not represent a verbatim account of the conversation, are challenged by Mrs Lacey and their weight must necessarily be affected by the fact any discussion occurred at a time of immense stress and grief with the funeral the following day. The notes suggest options were presented to Mrs Lacey. The compelling evidence is that no options were offered or discussed. Although Nurse Heaven fairly acknowledged she has no independent memory of the conversation, she says the notation "?" refers to Mrs Lacey questioning the decision. This interpretation does not sit comfortably with the flow of the words and is more consistent with doubt she made any decision at all.

Should Dr Wanat be referred to the Health Care Complaints Commission?

83. Dr Wanat's failing in the care of Mrs Lacey was not simply a case of not consulting with the parents to find out what they wanted although that in itself would be a serious omission in care. Rather he knew at the very least from their requests for the transfer to Sydney, a caesarean section and steroids, the parents wanted everything done to save Ty. Despite knowing their parents wishes they were ignored. The parents were presented with no option but for there to be no resuscitation.

84. This can only be described as a major and fundamental failing in the care of Mrs Lacey. It would be hoped against these glaring deficiencies Dr Wanat would have some insight and appreciation of his conduct.

85. Senior counsel for Dr Wanat submitted he does have insight and recognized "he didn't get it right". I disagree. There was in my view a distinct lack of candour in his evidence. Despite involvement in such a dramatic and unusual case and required to speak with Hospital management shortly after in response to complaints by the parents, Dr Wanat's recall of events was disconcertingly poor. Replies of "I don't remember" figured very prominently in his answers. This included his reply to the fundamental question whether he asked the parents what they wanted.

86. The submission was made that in accordance with the recommendation by Dr Challis, there was the involvement of a Paediatrician in the decision concerning resuscitation. I am of the view the Hospital records only support Paediatric involvement when the initial request to do everything was made by the parents. The notes are written by the Paediatric Registrar at 9.30 am but

[12] Brief p 239

refer to a call at 8.30 am consistent with the initial request by the family for everything to be done. The notes are silent on any reference to discussions with the parents concerning options for Ty.

87. Senior counsel said there are “good reasons” why the failure or deficiency on Dr Wanat’s part occurred. He referred in particular to two parts of the written statement of Dr Challis. The first was –“It is very unusual to offer intensive care before 24 weeks particularly outside a tertiary centre as it is generally futile”[13]. The simple answer to this is that Ty was not less than 24 weeks. The second part of the statement was –“if the couple ask for our advice it should be that the prognosis for the baby was poor and so it would be reasonable to offer that the baby not receive intensive care”. The submission overlooks the unchallenged evidence that Dr Challis told Dr Wanat to discuss it with the parents and ask them what they want. I cannot discern any basis to conclude there were “good reasons” to explain his conduct.

88. It is not possible to say with any certainty the reason for Dr Wanat’s conduct. Communication issues, stress, confronting a difficult case and level of experience have been raised in submissions. It should be remembered Dr Wanat was not a junior Doctor but rather a senior Registrar in Obstetrics and Gynaecology with extensive overseas experience.

89. There was throughout Dr Wanat’s written statements and evidence at inquest no acknowledgement of what overwhelmingly he failed to, namely to discuss the options and support the decision of the parents. There were as discussed above, written statements that are simply incorrect.

90. Dr Wanat was asked whether in light of his reading of the parents’ written statements he feels he should have made more effort to find out what they wanted. His reply was “most probably he should”. Any suggestion this showed some insight quickly evaporated when asked the question “why”. The response was rambling and non-responsive. He ultimately concluded there would have been no difference in the outcome.

91. I have concluded Dr Wanat’s lack of insight into his actions is of such concern that his conduct should be referred to the Health Care Complaints Commission for further investigation. The brief of evidence, findings and transcript of the evidence will be forwarded for their consideration.

Issue 5—the Response by the Hospital

92. It is important the Community has confidence in a Hospital taking appropriate steps to review major events affecting patient safety. One such mechanism is by a Morbidity and Mortality meeting. The NSW Health Policy Directive entitled “Deaths-Review and Reporting of Perinatal Deaths” requires a review of all perinatal deaths to “evaluate the circumstances surrounding the death including contributing factors and on the basis of such considerations develop

[13] Brief p 66

recommendations for improving processes of care ensuring feedback to clinicians."

93. What circumstances were in fact evaluated in Ty's case are unknown as quite remarkably, no minutes of the meeting were created. Mr Farrugia, Director of Clinical Governance at Wollongong Hospital told the inquest another person told him a meeting did occur and that it concluded the course taken of no resuscitation was appropriate. The lack of record keeping and consequent lack of accountability is on any view extremely disconcerting.

94. Mr Farrugia said following complaints by Mr and Mrs Lacey to the Hospital and the Health Care Complaints Commission, an investigation was conducted. It is said it involved the interviewing of staff. Yet Nurse Conte and Nurse Kerle apparently were not spoken too. Had they been asked, Nurse Conte would no doubt have told the Hospital that Mrs Lacey made it clear they wanted everything done to save Ty.

95. Mr Farrugia understood from the Hospital investigation the treating clinicians felt they had discussed the options with Mrs Lacey. The reference to treating clinicians can only reasonably be Dr Wanat. The overwhelming evidence is that no meaningful discussion occurred between Dr Wanat and the parents. It is most regrettable in neither the apparent Morbidity and Mortality meeting nor the Hospital investigation were the true circumstances uncovered.

96. Against these concerns it is at least pleasing to note the Hospital has introduced proforma documents to regulate the form and content of the minutes of meetings including provision for conclusions, recommendations and referral to Hospital management.

Issue 6-The Question of Recommendations

97. At the conclusion of the evidence, I circulated to the parties draft recommendations for comment.

98. Written submissions on behalf of the Health Districts argue a Guideline for the care and treatment of babies born in the grey zone of viability is "problematical". It is said the outcome for babies born in the grey zone may be affected by factors such as the mother's condition, any underlying diseases of the baby and level of maternity care. I do not understand how the outcome in a particular case impacts on the ability to set out the limits of the grey zone contained in the Consensus Statement.

99. It is said the information booklet available at the Royal Hospital for Women entitled "Outcome for Premature Babies" that is planned for a review could include a section dealing with babies in the grey zone and this would be sufficient in lieu of a Guideline. I do not agree. The booklet is an important education tool and its placement at all relevant Hospitals should be encouraged. However it would not address the need for Hospital staff to consider and discuss with the parents important issues of babies born at the threshold of viability.

100. The Health District suggests in lieu of a guideline, Wollongong Hospital should ensure staff is well acquainted with two documents. The first is the Consensus Statement. My concerns are --

- It is clear there was in fact no ongoing education as to the contents of the Consensus Statement, even though a Hospital Business Rule required reference to it.

- It should not require staff to work through a lengthy statement trying to identify the relevant principles such as gestational limits and principles of care. Moreover, in my view the Consensus Statement does not clearly express the views of all the experts at the inquest, namely that in a case such as with Ty, the ultimate decision on resuscitation and intensive care rests with the parents and should be supported by medical staff.

101. The second document referred to by the Health Districts that is said could be used for staff in lieu of a new Guideline is one entitled "Clinical Practice Guideline, Provision of Care to Mother and Foetus / Newborn at the Threshold of Neonatal Viability"[14]. My concerns about this proposal are –

- There is no evidence this document is used in New South Wales or that its conclusions and recommendations have expert approval. Indeed although it was produced by the Hospital in response to a request on my behalf for any relevant guidelines used by the Hospital not even Dr Davis, Director of Maternal and Paediatric Services had not seen it before.

- It invites confusion for staff to compare and contrast two statements concerning principles of care and resuscitation that are difficult to reconcile. The Consensus Statement deals with babies born 23--25 weeks with the option of resuscitation resting with the parents. The document "Provision of care to mother and foetus / newborn" deals with babies 20 -- 25 weeks and recommends at 24 weeks "almost all babies should be actively resuscitated".

102. The submission was made that existing Guidelines and Directions cover many of the issues in the proposed recommendations. I consider the issues raised in this inquest involve important medical and ethical matters that justify clear expression in a Guideline. To require staff to go from a Directive to a Business Rule without having relevant extracts of the Resuscitation Guidelines dealing with very premature babies invites uncertainty and lack of understanding of the guiding principles.

103. The Health Districts say a recommendation that states the decision of the parents on resuscitation is "paramount" could lead to a conflict between the interests of the child and those of the parents and may be contrary to law. I

[14] Brief p 484

disagree. I consider the case of *Application of JH, Re a Parent*[15] is distinguishable as the Court's jurisdiction could be invoked where the procedure requires consent outside the scope of parental responsibility. This would that would not apply in these circumstances. The simple point I am seeking to make with this recommendation is that the final decision concerning resuscitation and intensive care of babies born in the grey zone rests with the parents, not the treating Doctor or Hospital.

104. It was submitted there could be no concerns that counselling services were not available. I disagree to the extent that what was starkly missing was education of the parents as to what to expect with a stillborn baby, where no resuscitation occurs and their rights.

105. The question of the type of management plan in a Guideline was the subject of mixed views at the inquest. The arguments included—

- The danger it may be viewed as set in stone and applied without review.
- The difficulty in crystallising a plan that will often unexpectedly change with variations in the health of a mother or baby.
- Providing a copy to the parents may suggest their options to change has been removed.
- The need for transparency in decision-making and clarity of the parents wishes by a written document.
- The need in the event a copy is not provided to record the response of the parents to a plan.
- That a document may potentially avoid the dispute as to what advice was in fact given to parents in the event of an adverse outcome.

106. I consider there is merit in the interests of transparency and clarity in treatment of babies in the grey zone that a management plan be a requirement in the recommended Guideline.

107. Reference was made by the Districts to a recommendation for reinstatement of the Perinatal Advice Line and a Maternal Transfer Pack to assist parents to understand why a transfer is occurring and what to expect. Although both suggestions are laudable I do not believe either would have assisted in this case and should not form part of the recommendations.

108. Of the many articles referred to by the experts in their statements, one is of particular note. It said –

> "When things go wrong in the delivery room leading to complaint it is rarely due to a conflict of ethical opinion or uncertainty about the legal implications of clinical practice. Instead it is more commonly a reflection of inadequate counselling, uncertainty, staff confusion and tension surrounding an infants care"[16].

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[15] (2011) 80 NSWLR 354

[16] Brief p 180

109. The author referred to “the importance of having in place and implementing an agreed protocol on the management of infants of borderline viability which should include appropriate counselling of parents before delivery, the need for a detailed examination of the infant after birth and arrangements for care of the dying infant”. There is much to commend these observations in considering the draft recommendations.

The loss of a chance

110. There is no doubt this inquest has caused immense stress to Mr and Mrs Lacey. Their personal statement to the Court reveals the magnitude of their grief and sense of loss. It is impossible to imagine what they went through at Wollongong Hospital on 15 February 2010.

111. The inquest has however served a very important purpose. The desirability of continuity of care for High Risk patients has been highlighted. Strong arguments have been presented for a Guideline that addresses the difficult issues that can arise in the care of infants born in the grey zone and the need for education of staff and parents of this difficult time. It should be noted the parents have contributed with thoughtful and considered recommendations addressing many of these matters. It is hoped the parents will take some small comfort in knowing recommendations have been made that may reduce the chances of a similar outcome in the future.

112. Importantly, the inquest has empathically shown, contrary to an apparent Hospital investigation, that on the day Ty was born there was no consultation and agreement with the parents that there would be no resuscitation. The treating Doctor overrode the rights of Ty’s parents. The result was utterly devastating.

113. It is true there was a very significant risk Ty would not survive and if he did, a very significant risk of severe disabilities. But neither outcome was inevitable. By the treating Doctor not supporting the parents’ wishes, Mr and Mrs Lacey were denied in the most tragic of circumstances the chance for Ty they so desperately wanted.

114. The Court extends its sincere sympathies to the Lacey family.

Formal Finding

115. Ty Lacey died on 15 February 2010 at The Wollongong Hospital, New South Wales as the result of extreme prematurity.

Recommendations

116. **To the Minister for Health**-

Consideration be given to the creation of a Guideline for the care and treatment of extremely premature babies in the Grey Zone of viability that includes the following --

. The gestational limits of the grey zone of viability

. The need to develop an informed management plan available to the parents prepared after consultation between the clinicians and parents concerning on going treatment and the issue of intensive care and resuscitation

. The parents are advised as to their rights concerning treatment, resuscitation and end of life decisions

. The wishes of the parents as to resuscitation and end of life decisions are to be specifically obtained and are to be considered of paramount importance

. The management plan is subject to change at any time after consultation with the parents

. The need for education of the parents by way of an information package as to the stages of a high risk pregnancy including the risks to the mother and baby and what to expect in the event a baby is born stillborn or born alive but no resuscitation given

. The need for counselling services being available for the parents throughout the pregnancy and in particular after birth in the event a decision is made not to resuscitate

. The need for training of nursing and medical staff that encompasses the Australian Resuscitation Guidelines, end of life discussions with parents and explaining to parents the Palliative process in the event resuscitation is not to occur

. In the event of shared care management between Hospitals, the need for ongoing exchange of information including through multi disciplinary discussions concerning patient care and any management plan.

To Illawarra and Shoalhaven Local Health District

Consideration be given to —

. A review of the High Risk Clinic appointment scheduling to improve continuity of care of a high-risk patient

. Education of staff of the importance of accurate recording of the minutes of Morbidity and Mortality meetings including conclusions and recommendations for consideration by Hospital management and that there be a regular audit of compliance

Ian Guy
Deputy State Coroner
Wollongong

11 December 2012